

Members

Sen. Marvin Riegsecker, Chairperson  
Sen. Rose Antich  
Rep. Sheila Klinker  
Rep. Robert Alderman  
Thomas E. Van Meter  
Sylvia Brantley  
Suda Hopkins  
Joanne Rains  
Betty Williams  
Sally Lowery  
Ervin Picha  
Christopher Durcholz



# INDIANA COMMISSION ON MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

LSA Staff:

Carrie Cloud, Attorney for the Commission  
Casey Kline, Attorney for the Commission  
Kathy Norris, Fiscal Analyst for the Commission

Authority: P.L. 272-1999

**Legislative Services Agency**  
**200 West Washington Street, Suite 301**  
**Indianapolis, Indiana 46204-2789**  
**Tel: (317) 233-0696 Fax: (317) 232-2554**

## MEETING MINUTES<sup>1</sup>

**Meeting Date:** October 4, 2001  
**Meeting Time:** 10:00 A.M.  
**Meeting Place:** State House, 200 W. Washington  
St., Senate Chambers  
**Meeting City:** Indianapolis, Indiana  
**Meeting Number:** 4

**Members Present:** Sen. Marvin Riegsecker, Chairperson; Rep. Sheila Klinker; Thomas E. Van Meter; Sylvia Brantley; Suda Hopkins; Ervin Picha.

**Members Absent:** Sen. Rose Antich; Rep. Robert Alderman; Joanne Rains; Betty Williams; Sally Lowery; Christopher Durcholz.

Senator Riegsecker called the meeting to order at 10:35 A.M. Senator Riegsecker told the Commission that he had been informed that the Indianapolis law firm of Lowe, Gray, Steele and Darko would soon be filing a lawsuit on behalf of residents of Muscatatuck State Developmental Center (MSDC) to try to stop the closure of the center.

---

<sup>1</sup> Exhibits and other materials referenced in these minutes can be inspected and copied in the Legislative Information Center in Room 230 of the State House in Indianapolis, Indiana. Requests for copies may be mailed to the Legislative Information Center, Legislative Services Agency, 200 West Washington Street, Indianapolis, IN 46204-2789. A fee of \$0.15 per page and mailing costs will be charged for copies. These minutes are also available on the Internet at the General Assembly homepage. The URL address of the General Assembly homepage is <http://www.ai.org/legislative/>. No fee is charged for viewing, downloading, or printing minutes from the Internet.

**Senator Johnny Nugent, District 43 (Dearborn, Franklin, Jefferson, Jennings, Ohio, Ripley, Switzerland, Union)**

Senator Nugent thanked the Commission for traveling to MSDC for its most recent meeting and for considering issues related to the closure of the center. Senator Nugent expressed his concern for the safety of the current residents of MSDC, particularly those who require 24-hour care, if they are moved into community settings. He noted that many of the residents of MSDC have been there for over 30 years and that moving these individuals to any other setting and away from MSDC employees who are like family to them would be devastating. Senator Nugent expressed his belief that the state cannot afford to close MSDC, especially in light of the state's current fiscal situation. He stated that estimates of the Family and Social Services Administration (FSSA) indicate that the cost of closing MSDC will be \$25 million more than the cost of operating the center for the same time period, and this estimate does not include the cost of providing care in the community once the residents move. He noted that if the state cannot afford to give its employees pay raises right now, it cannot afford to spend the money to close MSDC, which is now fully recertified to receive federal Medicaid funds. Senator Nugent expressed his opposition to the decision to close MSDC, stating that it was motivated primarily by fiscal concerns. He said that even assuming that MSDC residents could receive care in the community for less money, he is concerned that they would actually be receiving less care. Senator Nugent urged the Commission to support him in an effort to slow down the closure process by removing or at least extending the announced closure deadline of December 2003. He stated that the continued operational costs of the center might be able to be somewhat alleviated by divesting the state of center acreage that is no longer needed.

**Olmstead**

**Alison Becker, Director, Fiscal Services, Division of Disability, Aging, and Rehabilitative Services (DDARS)**, informed the Commission that the federal Centers for Medicare and Medicaid Services (CMS, formerly known as the Health Care Financing Administration or HCFA) has approved FSSA's application for a new developmental disabilities (DD) Medicaid waiver.

Ms. Becker, who also serves as FSSA's *Olmstead* Coordinator, reminded the Commission that in 1999, the Supreme Court of the United States issued its decision in the *Olmstead* case, holding that individuals with disabilities have the right to live in the least restrictive, most-integrated environment possible. In response to this court decision, Governor O'Bannon directed FSSA to put together a report of Indiana's status in allowing individuals with disabilities to live in the most-integrated settings. That report was delivered to the Governor on June 1, 2001. (Ms. Becker noted that she had provided a copy of that report, entitled *Indiana's Comprehensive Plan for Community Integration and Support of Persons with Disabilities*, to the Commission at its meeting on August 30, 2001.) Ms. Becker explained that the report, which presented information concerning Indiana's goals for the next biennium for providing services to individuals with disabilities, recommended the formation of a Community Choice Commission to establish Indiana's long-term plan for providing comprehensive services to individuals with disabilities. The Commission, which will consist of state agency personnel, individuals with disabilities, advocacy groups, and other interested parties, including the legislature, is currently being established, and will not replace the Southeast Regional Committee, the Community and Home Options to Institutional Care for the Elderly (CHOICE) Board, or any other existing body. Ms. Becker noted that the Commission is likely to address issues raised at recent forums held around the state, including accessible and affordable housing, transportation, availability of

dependable caregivers, and self-directed care.

Ms. Becker informed the Commission that FSSA is also currently working on implementing SEA 215-2001 dealing with self-directed care. FSSA is currently developing a registry for caregivers and is amending the autism, medically fragile children, and aged and disabled Medicaid waivers to provide for self-directed care.

Responding to a question, Ms. Becker stated that the new DD waiver will allow a registered nurse or licensed practical nurse to provide health care coordination (e.g., medication, doctors' appointments, general health care treatment plan) to a consumer. The new DD waiver also includes reimbursement to both providers and individuals for transportation to community events. The ultimate goal of the DD waiver is to assure that recipients receive all the care and services that they need. Ms. Becker also noted that targeted case management is now a part of the state's Medicaid plan. This will allow developmentally disabled individuals who meet Medicaid eligibility criteria but who are on a waiver waiting list to receive case management services that will help tie these individuals into community supports and other state services. The state's share of funding for the DD waiver (approximately 38% of the total cost) will come from resources previously allocated to DDARS and will not affect anyone already receiving services. Ms. Becker noted that the new DD waiver includes about 2,000 new slots for the first year, and the ability to add more slots if additional funding becomes available. FSSA's current plan is to move approximately 1,500 individuals from fully state-funded services onto the DD waiver, thus moving some individuals off the waiting lists.

Responding to a question, Ms. Becker remarked that the *Olmstead* decision will have an impact regardless of the closure of MSDC, as the court's decision applies to services provided to individuals regardless of the setting in which those services are provided (i.e., whether in an institutional or a community setting).

### **Governor's Council on State-Operated Care Facilities**

**Chris Newman, Director, Bureau of Quality Improvement Services, DDARS**, provided the Commission with a copy of the final report of the Governor's Council on State-Operated Care Facilities. (See Exhibit 1.) She stated that this council was created by Governor O'Bannon in September, 1999, to develop a long-range plan to ensure the provision of high quality, cost-efficient care in the eleven care facilities operated by the state (i.e., state developmental centers for individuals with developmental disabilities {Muscatatuck and Fort Wayne}, psychiatric hospitals {Larue D. Carter, Evansville Psychiatric Children's Center, Evansville State Hospital, Logansport State Hospital, Madison State Hospital, Richmond State Hospital}, the Soldiers' and Sailors' Children's Home, Silvercrest Children's Development Home, and the Indiana Veteran's Home). The council's main recommendation was that with the exception of the Soldiers' and Sailors' Children's Home and the Indiana Veteran's Home, services should be regionalized, with the state divided into eight regions. Ms. Newman explained that the number of beds, both for individuals with developmental disabilities and individuals with mental illness, would vary from region to region depending upon a particular region's needs and resources. Ms. Newman also noted that the council determined that a single 100-bed high-security facility should be sufficient to meet the state's needs. She also expressed the council's concern that a quality assurance process be in place to ensure that regionalized services are provided in the best manner possible.

Responding to a question concerning the proposed number of beds to be included in the Southeast region, **Steve Cook, Deputy Director, Bureau of Developmental Disabilities**

**Services, DDARS**, stated that FSSA's current plan is to have 150 beds in that region, 90 for individuals with serious mental illness and 60 for individuals with mental retardation/developmental disabilities.

Responding to a question regarding what the relationship of a regional center will be to community-based providers, Ms. Newman noted that the council's report recommended the development of local and regional community planning councils to help link the center with providers, clients, and families, possibly utilizing existing Step Ahead councils.

Ms. Newman acknowledged that before the regional service center plan could be implemented in any particular region, there must be adequate service providers in the region to provide the services needed.

### **Mortality Review Process**

**Chris Newman, Director, Bureau of Quality Improvement Services, DDARS**, informed the Commission that FSSA's mortality review committee was established in January, 2000, and implemented in February of that year. The purpose of this committee is to review the deaths of residents in state developmental centers, private intermediate care facilities for the mentally retarded (ICF/MRs), and community settings. The committee's membership includes Ms. Newman and members of her staff, personnel from DDARS' Bureau of Developmental Disabilities Services and Bureau of Aging and In-Home Services (including a licensed nurse), Adult Protective Services personnel, the Developmental Disabilities Ombudsman, a physician with experience in the area of mental retardation/developmental disabilities, staff from FSSA's Office of General Counsel, and Indiana State Department of Health personnel. The committee meets monthly to review cases and looks at all relevant documents relating to a client's death, including incident reports, death certificate, autopsy report, and internal provider information. Committee recommendations may be either systemic or provider-specific. Since February 1, 2000, the committee has reviewed and closed 122 cases. Of these cases, 47 represent deaths which occurred in group homes (representing 1.35% of all group home residents), 8 represent deaths which occurred in state developmental centers (representing 1.34% of all state developmental center residents), 14 represent deaths which occurred in large private ICF/MRs (representing 2.01% of all large private ICF/MR residents), and 30 represent deaths which occurred in waiver settings (representing 1.96% of all waiver residents). Currently, the committee has 24 open cases, one of which cannot be reviewed at this time due to pending litigation. The average review time for a case is three months.

Some Commission members expressed concern about the availability and quality of caregivers to provide care to individuals in community settings. Ms. Newman acknowledged that there are many challenges in this area, including the stress to a client that occurs when caregivers who are not familiar with the client's particular needs are sent to the client's home. She noted that FSSA is working on addressing these issues, including recommending that providers assure that all caregivers on staff are aware of the needs of each individual for whom the caregiver will be providing care and encouraging case managers, who are likely more aware of the individual's needs, to help in that training. In response to other issues that were raised, Ms. Newman stated that FSSA is working on addressing higher pay and better training for caregivers and delay in payment to providers from the state.

### **Group Homes**

**Gerald Coleman, Assistant Commissioner, Health Care Regulatory Services, Indiana State Department of Health (ISDH)**, provided the Commission with a handout summarizing the federal regulations regarding active treatment in group homes (Exhibit 2) and a document that is provided to the families of individuals who are determined to no longer require active treatment (Exhibit 3). Mr. Coleman reminded the Commission that the ISDH is the agency responsible for enforcing federal regulations regarding group homes and that a couple of years ago, CMS (formerly HCFA) instructed the ISDH to begin a stricter enforcement of regulations W197 and W198 concerning active treatment (i.e., treatment aimed at teaching an individual skills necessary to live in a more independent setting than a group home). An ISDH finding that an individual living in a group home no longer requires active treatment results in the group home losing its Medicaid certification unless that individual is relocated from the group home. Historically, the transition time allowed for an individual to be relocated was approximately 90 days. After discussions with CMS and FSSA, that transition time may now last as long as seven months, or possibly even longer if the group home disputes the ISDH's determination regarding active treatment. Mr. Coleman noted that in March, 2001, the ISDH conducted training for group home operators and staff concerning W197 and W198 issues. Mr. Coleman informed the Commission that from September 1, 2000, to September 1, 2001, the ISDH made 159 citations regarding W197 and W198 as compared to 82 citations for September 1, 1999, to September 1, 2000.

In response to a question regarding why Indiana appears to have more W197 and W198 findings than other states, Mr. Coleman explained that Indiana has more group homes than many other states and that CMS has not specifically ordered other states to strictly enforce these particular regulations.

**Steve Cook, Deputy Director, Bureau of Developmental Disabilities Services, DDARS**, commented that although W197/W198 citations are a regulatory compliance issue, they are also a people issue. Some group home residents who would like to move to a more independent setting are glad to receive a citation. However, other individuals who do not yet feel prepared to move out of a group home are devastated by such a finding. Mr. Cook noted that the extended transition time has been very helpful in allowing time to prepare a person-centered plan for the individual moving out of the group home, to determine whether the individual is eligible for Medicaid waiver services, and to secure a new placement. Mr. Cook stated that in 2001, DDARS has developed budgets for over 100 individuals with W197/W198 findings and most of these individuals have been waiver eligible. Mr. Cook commented that most individuals who are relocated from group homes due to W197/W198 citations continue to receive 24-hour care, just not continuous, aggressive active treatment as provided in the group home. He commented that often a large part of the stress involved in W197/W198 situations is a lack of understanding by the families regarding what care their loved one will receive in the new setting.

Mr. Cook provided the Commission with a copy of SEA 375-2001 (Exhibit 4). This act allows more than four individuals with W197/W198 findings to remain in a group home for up to one year while the home converts from a group home to a supported living setting. To date, nine group homes have converted to supported living settings.

Responding to a question, Mr. Cook stated that there are some indications that CMS may reverse its position regarding Medicaid waivers and may at some point require a waiver for an individual to be eligible for institutional care. (Current CMS policy requires a waiver for an individual to receive care in a non-institutional setting.) However, this policy change, if it occurs, is not likely to occur soon.

**Costa Miller, Executive Director, Indiana Association of Rehabilitation Facilities,**

noted that the ISDH's increased enforcement of W197/W198 regulations was the direct result of federal government intervention. He also commented that the ISDH has been doing everything it can to assist providers in this situation, including conducting training on the active treatment issue and promptly reviewing refuted citations.

### **First Steps**

**Tracy Mitchell, Bradley and Associates**, informed the Commission that in early 2001, he conducted a study of the Infants and Toddlers with Disabilities program (First Steps) for FSSA in order to look at areas concerning program controls and accountability. He provided the Commission with a handout detailing the 17 recommendations he made in his report, including the action that has been taken on the recommendations to date. (See Exhibit 5.) Mr. Mitchell noted that First Steps is subject to many federal regulations, thus creating some difficulties in what actions the state may take. For example, federal regulations require that a child's team develop the Individual Family Service Plan (IFSP) for the child, which determines the type and amount of services the child receives. This regulation prevents the state from imposing prior authorization requirements in an effort to control the utilization of services. Mr. Mitchell acknowledged that some of his recommendations are more controversial than others. For example, he stated that requiring a parent's signature for all services to ensure that the services are actually delivered is generally not a cause for dispute and has already been implemented by FSSA. However, recommendations that regional System Points of Entry (SPOEs) replace the current county-level SPOEs and that the determination of the type and quantity of services needed by a child are not made by an individual who will also be providing some of those services are the subject of a good deal of dispute.

Responding to a question regarding providing services in a child's home, Mr. Mitchell stated that the "natural environment" requirement of First Steps is a complicated issue. On one hand, providing services in the child's home is more expensive than providing services in a facility-based setting, largely due to instances where a provider arrives at a child's home to provide services and the family is not home. In addition, there are sometimes safety concerns for a provider to go into certain areas or certain homes. On the other hand, the biggest argument in favor of providing services in the child's home is that the provider is not just providing services to the child for a short period of time, but is actually training the family to provide services to the child at times when the provider is not there. However, there are also recognized advantages in providing services in an integrated setting, including allowing a child and the child's family to interact with other individuals in similar situations. Mr. Mitchell noted that one of the main factors in the debate over natural environment is that First Steps changed very rapidly from a facility-based model to a home-based model. He commented that ultimately, the choice of setting should belong to the family.

Responding to a question regarding recommendation 16 (provider credentialing), Mr. Mitchell noted that this process, which is not yet in place, is not accreditation as was discussed as a possibility last year, but would be more of a paperwork type process to assure that providers are adequately trained. This would also help provide families with more information to use in choosing a provider.

Mr. Mitchell stated that recommendation 15 (adopting home health payment rates) will most likely not be implemented. One reason for this is that the billable service units for home health care are different than the service units for First Steps, thus the initial projected savings are likely overestimated. In addition, it is currently difficult to get home health care services due to the payment rates, thus adopting these rates for First Steps

might cause a problem in access to services in this program as well.

**Bob Marra, Assistant Superintendent, Indiana Department of Education (DOE),** provided the Commission with a handout concerning conflicts between the federal and state regulations regarding transmission of information from Part C (First Steps) of the Individuals with Disabilities Education Act to Part B (special education for children ages 3 through 21). (See Exhibit 6.) Both federal and state regulations require the consent of a child's parent for specific information regarding the child to be transmitted from Part C to Part B. Under a proposed amendment to federal Part C regulations, the First Steps program would be allowed to transmit directory information regarding a child to the local school corporation without first obtaining parental consent so that the corporation would know that the child will be coming into the school system. State regulations provide that a transition conference be held, with approval of the child's family, between the First Steps service coordinator, the child's family, the school corporation that the child will be attending, and the child's current and potential service providers at least 90 days and as much as 6 months before the child's third birthday to review the child's needs and to establish a transition plan for the child.

Mr. Marra stated that based on a study conducted by DOE and FSSA in 2000, 25% of First Steps children transitioned directly from First Steps into special education. The survey did not collect data concerning whether any students in the special education program had ever participated in First Steps but had not gone directly from one program to the other.

Mr. Marra also discussed the following issues concerning the transition of a child from First Steps into Part B special education:

- Level of intensity of services. Some Part B service providers have expressed concern regarding the correlation between the nature of a child's disability, the amount of First Steps services the child received, and the progress made. Mr. Marra suggested that First Steps might look at implementing some type of guidance document that would recommend the appropriate level of services based on a child's particular disability.
- Checks and balances. Some Part B service providers noted that there often seems to be no system of checks and balances between the amount of First Steps services requested by a child's family or provider and the amount of services the child receives, particularly when the service provider is also on the team that evaluates the child's needs. Mr. Marra echoed Mr. Mitchell's recommendation that the First Steps program might look at requiring an independent provider to participate in the assessment of services needed by a child.
- Different model. First Steps looks mostly at a child's developmental needs, while special education looks at the child's educational needs. This difference in focus is often difficult for families to adjust to.
- Eligibility. First Steps has a very broad definition of who is eligible for services. Although DOE has expanded the definition of eligibility for Part B services to include developmental disabilities, First Steps eligibility is still much broader than Part B, so many First Steps children will not qualify for Part B services.
- Service delivery model. Under First Steps, families choose their child's providers from a list of approved providers. However, under Part B, the school corporation chooses the providers.
- Children with late spring birthdays. First Steps services are provided year-round. However, schools operate on a 180-day school year. Services are available outside of the normal school year (e.g., over the summer), but it is often difficult to get First Steps children with birthdays in late spring into the special education system in time to make sure that there is not a delay in transitioning between programs.
- Location of services. In First Steps, services are provided in the child's natural

environment, which is often the child's home. However, in Part B, while the school is required to pay for the services a child needs, there is no requirement that the school actually provide those services on its own premises (i.e., the child may be required to go to a location other than the school to receive services).

In response to questions, Mr. Marra indicated that the DOE does not currently have any suggested legislative proposals concerning the correlation of First Steps and Part B special education but may have some suggestions after reviewing Mr. Mitchell's recommendations. He commented that the First Steps program is very important and should continue in operation because the early intervention services provided under the program help to reduce the need for special education services which are generally more expensive to provide than First Steps services. He also indicated that only about 25% of the funding for special education comes from the federal government.

### **Next Meeting & Adjournment**

Senator Riegsecker reminded the Commission members that the Commission's final meeting will be held Wednesday October 24, 2001, at 10:00 A.M. in Room 233 of the State House. At this meeting, the Commission will consider its final report and possible legislation. Senator Riegsecker urged all Commission members to attend as it is necessary to have a quorum present for the Commission to take any official action on a final report or to recommend a bill draft.

There being no further business to come before the Commission, Senator Riegsecker adjourned the meeting at 1:20 P.M.